How Accurate is Information that Patients Contribute to their Electronic Health Record?

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Abstract

Increased patient interaction with medical records and the advent of personal health records (PHRs) may increase patients' ability to contribute valid information to their Electronic Health Record (EHR) medical record. Patient input through a secure connection, whether it is a patient portal or PHR, will integrate many aspects of a patient's health and may help lessen the information gap between patients and providers. Patient reported data should be considered a viable method of enhancing documentation but will not likely be as complete and accurate as more comprehensive data-exchange between providers.

Background

Accurate and complete data are critical for patient care but are also becoming increasingly important to support quality measurement for pay for performance initiatives. Data used to support clinical care and quality improvement must be comprehensive and as up-to-date as possible. Currently, medical practitioners and staff provide all documentation into EHRs. However, the result of this is that valuable medical information is often missing or out of date which may compromise patient care and quality measurement. Patients have the ability and incentive to report additional information, helping to create a more complete medical record. Nonetheless, few mechanisms currently exist to facilitate this information sharing.

EHRs must move toward a more structured format that reduces inaccuracies and offers dependability for physicians and researchers. One study found that 25% of sampled patients believed some information in their medical record to be incorrect.[1] In fact, the true proportion is undoubtedly much higher. Medication errors due to insufficient information about patients and drugs comprise nearly half of serious medication errors.[2] For this and other reasons, EHRs must make clinical data accessible to the physician to avoid poor quality decisions and adverse events.[3] The most recent Medical Records Institute Survey on EHRs reported that an overall 73.1% of physicians and nurses reported the need to reduce medical errors as a major reason to implement EHRs.[4] Improved communication between patients and providers will facilitate documentation.

More and more, physicians and patients are working together, increasing the exchange of information and sharing the decision-making. The collaborative care model advocates for the patients' expertise of his/her own life to complement the physician's knowledge of diseases when discussing health maintenance.[5] Chronic disease treatment often involves coordinating shared care with a specialist that could also benefit from information provided by the patient[6] When physicians incorporate the patient as a partner in clinical decisions they help to encourage confidence and promote a healthier lifestyle.[7] Responsibility of care is shifting towards the patient[8] alleviating the formally one-sided effort of physicians.

Technology is easing the transition towards a more patient-centered healthcare model by providing a fast, convenient way for patients to access their records and electronically provide information to their physician's office.[9] According to a recent Harris Interactive Poll, a majority of patients (78%) surveyed online feel personal records offer the opportunity to provide doctors with useful information.[10] Patients and physicians agree that patient access to medical records helps facilitate communication and patients' understanding of their conditions.[11]

Primary-care practices have experimented with patients gathering their own data to be viewed by their physician. When asked about history of skin cancer, patients were able to report a specificity of basal cell carcinoma with 71.8% accuracy.[12] Similarly, patient-reported data was found to be more

valuable than notes from their general practitioner when determining risk for colorectal cancer.[13] In the case of children, parents provided aspects of their children's past medical history such as birth status, allergies, current medications, immunization status, and previous hospitalizations with 94% to 99% accuracy across subjects.[14]

Continuous innovations in medical science as well as the trend toward preventive medicine have broadened the personal health information that doctors maintain for each patient.[8] Some medical conditions such as diabetes require more communication[15] and largely benefit from shared medical records that make interaction more frequent and data available to both physicians and their patients whenever convenient. Communication around medications is essential for maximizing therapeutic benefits to patients and minimizing the amounts of discrepancies between prescribed medication and what the patients are taking.[16,17]

This study aims to assess the extent to which patient reported information could enhance medical record and quality measurement data. Patients' knowledge of their health maintenance items and participation in preventive care were assessed by evaluating patient-reported data for its conformance with EHR data, which is entered by medical professionals only.

Methods

Partners Healthcare, a collaborative health care system based in Boston, has offered an ambulatory EHR or Longitudinal Medical Record (LMR) to affiliated providers since 1999. Currently only authorized employees can access and update the LMR.

This study involved 6 practices, 44 physicians and a total of 140 office staff. Patients from these practices were invited to complete one or more online surveys through the Partner's Healthcare System secure web-based patient portal, *Patient Gateway.* The initial recruitment message, reminders, study consent process and access to the surveys was all within *Patient Gateway.* The surveys were developed by the Foundation for Accountability (FACCT). All participating patients were offered a general health survey. Patients whose ambulatory medical records indicated such problems as Asthma or Diabetes were also offered corresponding surveys addressing these clinical areas.

One out of every 4 patients was randomly selected to be offered a depression survey regardless of whether any depression issues were identified in the LMR. Upon completion of the depression survey, patients were presented with the assessment result of their risk (high, moderate, low) for depression.

Patients were sent up to four invitation messages to encourage them to review the consent form within *Patient Gateway.* Patients received a survey invite immediately after consent which was followed by up to four reminders to complete the survey.

A total of four possible surveys were used to assess the extent to which patient reported information could enhance medical record and quality measurement data. Respondents were asked to recall specific test results as well as whether or not a test was performed within a certain time frame. Data collected through Patient Gateway using the FACCT patient survey was compared with data available in the LMR at the time of the survey. Following the recommendation guidelines[1] for each health measure, it was determined which patients should have had a procedure completed. Analysis of the data provided a percentage of time a result from each procedure was represented in the LMR as well as reported in patient surveys. Patient responses to questions were evaluated for their ability to provide data that otherwise could not be found in the LMR. If valid values were provided by both patient surveys and LMR, then data was assessed for whether the two values matched within specified criteria. If data could not be found in either the LMR or patient survey for a patient who is recommended to have had a procedure due to age or gender (specified in Table 1), the data is defined as missing.

Results

In this study, 1094 out of 6008 invited patients participated. Respondents were predominantly white (86%), 55% female, with a mean age of 47.4 years, similar to the invited population. Patients were able to report general information such as height and weight that otherwise was missing 94%-95% of the time in the LMR (Table 1). Height was missing from the LMR (64%) more often than weight (19%). Results show that patients frequently are not able to report specific values of general health measures as can be seen in the percentage of records where values were missing for blood pressure (46%) and cholesterol (71%-86%). However, it is likely that a portion of these patients may have not have had cholesterol screening in this care setting since these values are also missing in the LMR at least 40% of the time. Only 12% of the patients who had cholesterol data available in the LMR, but did not report a value in the survey, had total cholesterol levels of greater than 240. This could signify that specific results are not always disclosed to patients

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[1] Recommendation guidelines were taken from those in use at Brigham and Women's Hospital to support physician reminders, many of which are taken from the US Preventive Task Force.

and those who are told may not remember specific results that fall within the normal range. However, whenever there were valid measurements in both the EHR and patient surveys, patients' ability to report their values within specified criteria ranged from 70 to 88% with an exception of height, in which patients were 100% accurate within 2 inches.

Table 1. Absence in Electronic Medical Records and Patients' Ability to Report

Health Measure	% missing in LMR	% missing in patient survey	% missing that pt provided***	% with values in both	% match when 2 values available	Match Criteria
Height	64%	3%	95%	33%	100%	within 2 inches
Weight	19%	5%	94%	76%	86%	within 10 pounds
Total Cholesterol	40%	71%	6%	26%	88%	within 20 points
LDL	44%	86%	1%	13%	70%	within 10 points
HDL	45%	84%	3%	14%	80%	within 5 points
Blood Pressure*	<1%	46%	0%	36%	71%	systolic w/in 20 pts diastolic w/in10 pts
HbA1c**	0%	55%	0%	45%	77%	within 1 point
Pap smear *(women only)*	4%	2%	100%	94%	86%	ever had yes/no
Mammogram *(women ≥ 50 yrs)*	<1%	3%	100%	96%	85%	ever had yes/no
Stool Test *(patients ≥50 yrs)*	74%	12%	82%	24%	90%	ever had yes/no
Proctoscopic Exam *(patients ≥50 yrs)*	60%	19%	76%	36%	78%	ever had yes/no
Eye Exam *(patients ≥66)*	92%	8%	90%	<1%	89%	ever had yes/no
Influenza Vaccine *(patients ≥51)*	62%	5%	59%	36%	67%	had in last 12 mos.
Pneumonia Vaccine *(patients >66)*	54%	15%	49%	38%	83%	ever had yes/no

*missing data refers to either one or both systolic & diastolic are not reported; valid values are only when both systolic & diastolic values are present in both the LMR and patient report

**diabetic patients only (n=29)

***percent was calculated by number of patients providing information /number of patients with missing information in the LMR

The small size of the diabetic sample was aggravated by the fact that 59% of diabetics responding to the survey did not report their HbA1c level, a critical value in managing their disease. Of these patients, 31% had HbA1c levels over 7.0 indicating that their condition is not being sufficiently controlled.

For quality measures requiring only knowledge of whether or not the test was done, patients did a little better on average (85% - 90%). For health maintenance screenings such as Cervical Cancer Screening (Pap smear) and Faecal Occult Blood Test (Stool Test) requiring only a yes or no answer, patients' answers were missing less than 20% of the time and matched the LMR for 67%-90% of patients.

Patients were able to report health maintenance screening information missing from the LMR at least half the time although it ranged from 49%-100% depending on the specific test. When valid information was available from patients and in the LMR, patients' responses were consistent with the LMR more than 75% of the time with the exception of influenza vaccine (67%).

Ninety-three percent (93%) of patients invited to complete a depression survey completed this screening survey. Approximately three quarters of the patients whose answers indicated a high or moderate risk did not have depression on their LMR Problem List (Table 2). Physicians may not always be using the problem list to record clinical issues. However, since questions in the depression screening tool referred to feelings within the last two weeks, it is also possible that these patients had a new problem involving depression for which they had yet to seek care.

Table 2. Depression Screening Compared LMR Problem List

Depression Screening	Depression on LMR Problem List	No Depression on LMR Problem List	Total Participants
High Risk for Depression	4 (25%)	12 (75%)	16 (100%)
Moderate Risk for Depression	7 (27%)	19 (73%)	26 (100%)
Low Risk for Depression	20 (9%)	192 (91%)	212 (100%)
Total	31	223	254

Patients have the ability to classify the severity of their asthma which may assist physicians in better understanding the patient's actual or at least perceived condition, both allowing physicians to better care for their patients. The option to designate severity of asthma does exist in the LMR but was missing for 71% of respondents with asthma. Only 16% of those patients who consider the severity of their condition to be major have this same impression reflected in the LMR. Among them, one patient who considered his asthma to be severe did not have a designation of major anywhere in the LMR. This may be of particular importance for those patients identifying themselves as moderate or severe for whom only a minor designation or no designation exists in the LMR.

Discussion

This study demonstrates that the LMR is often incomplete and that additional data would be useful in a variety of ways for improving the quality of patient care. Furthermore, the results suggest that patient-reported data is a promising source of general health information. Fragmentation of a patient's health care makes it difficult for physicians to maintain a comprehensive medical record. Without a unified EHR, physicians often ask patients to contribute clinical results from differing providers.

Patients can often report valuable information on the presence or absence of tests. The proposition of pay for performance in preventive medicine relies on presence of timely screenings and consistent quality measurement. Physicians must have access to complete patient information before their effectiveness in educating patients can be evaluated.

Patients' ability to report specific results of tests (such as cholesterol levels) was less reliable than data in the LMR. Patients rely heavily on their healthcare providers to document and share their test results and therefore, may not recall specific results but rather whether or not the result fell within the normal range.

Patients often reported that they had findings of depression, when this was not noted in the problem list. Asking patients to fill out surveys about areas like quality of life may be one of the most useful parts of personal health records helping to support early interventional treatment, when necessary.

Patients have important knowledge of their basic health maintenance, and can and should assist physicians in recording information. Patient access will increase the quality of this data to help ensure that the physician has the most comprehensive file possible with which to work. In addition to improving quality assurance, patient provided data and patient access to LMR data will help increase communication between provider and patient.

Limitations

This study did not contain a formal process to verify whether or not the patient-provided information was accurate but only confirmed its validity as a possible response. The results of this study may not be generalizable to other healthcare institutions because all invited patients were already using the patient portal Patient Gateway suggesting they may be more active in their healthcare than the average patient. This is expected as the study was conducted within an academic, urban healthcare system. In addition, there was a low response rate of 18% and respondents were predominantly white.

Conclusion

Historically, much of clinical information stored in an EHR has always reflected information reported by patients to their providers, who then document that information in the record. Patients have been given opportunities to review and correct information in the record, typically during an office visit. Now, EHR and patient portal technology create more opportunities to review and correct information, but it should continue to be done with the oversight of medical personnel who can apply medical judgment to the completeness and correctness of the information in the record. Moreover, the medical record must be presented in a patient-friendly manner to ensure patient understanding.

Increased patient interaction with medical records and the advent of PHRs may increase patients' ability to contribute valid information. Patient input through a secure connection whether it is a patient portal or PHR, will integrate many aspects of a patient's health and may help lessen the information gap between patients and providers. Patient reported data should be considered a viable method of enhancing documentation but will not likely be as complete and accurate as more comprehensive data-exchange between providers.

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